Ethics That Exclude: The Role of Ethics Committees in Lesbian and Gay Health Research in South Africa

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A B S T R A C T

Prevailing state and institutional ideologies regarding race/ethnicity, gender, and sexuality help to shape, and are influenced by, research priorities. Research ethics committees perform a gatekeeper role in this process.

In this commentary, we describe efforts to obtain approval from the ethics committee of a large medical institution for research into the treatment of homosexual persons by health professionals in the South African military during the apartheid era. The committee questioned the "scientific validity" of the study, viewing it as having a "political" rather than a "scientific" purpose. They objected to the framing of the research topic within a human rights discourse and appeared to be concerned that the research might lead to action against health professionals who committed human rights abuses against lesbians and gay men during apartheid.

The process illustrates the ways in which heterosexism, and concerns to protect the practice of health professionals from scrutiny, may influence the decisions of ethics committees. Ethics that exclude research on lesbian and gay health cannot be in the public interest. Ethics committees must be challenged to examine the ways in which institutionalized ideologies influence their decision making. (*Am J Public Health.* 2001;91:865–868)

Central to South Africa's democratic transformation have been attempts to understand how and why apartheid human rights abuses occurred. The Truth and Reconciliation Commission was established to document gross human rights abuses during apartheid, to consider amnesty for those accused of such abuses, and to propose reparations for the victims. The Truth and Reconciliation Commission health sector hearings detailed how apartheid ideology "permeated the entire health sector, distorting and corrupting health professional training, research and service delivery,"[1(p976)] resulting in large-scale human rights violations.[2,3] Health professional institutions, including research organizations, not only failed to address institutionalized racism, sexism, and heterosexism within health provision but also actively perpetuated a myth of "scientific objectivity" and political "neutrality" that served to bolster this profoundly unjust system.[4]

In South Africa, the close relations between racist ideologies and health research have begun to be documented.[2,3,5,6] Prevailing state and institutional ideologies regarding race/ethnicity, gender, sexuality, and so on help to shape, and are in turn influenced by, research priorities.[7,8] King[9(p32)] noted that in the United States, "The systemic exclusion of minority populations from biomedical and sociobehavioural research . . . represents a form of institutional racism." Lesbians and gay men are a minority group who often have also been excluded from health and other research. Indeed, Chauncey et al.[10(p1)] have commented that research on the history of homosexuality "has been constrained by the intolerance of governments and academics alike. . . . Repression and marginalization have often been the lot of historians of homosexuality as well as of homosexuals themselves." Attempts to censor research on gay and lesbian issues are a form of institutional heterosexism—a systematic casting of homosexuality as inferior to heterosexuality rather than discrimination at an individual level.[11,12]

Research on gay and lesbian health can be viewed as socially sensitive research because of the potential social consequences for the participants, the class of individuals represented in the research, or both.[13] Such research often highlights the complex ideologic and ethical issues underlying the research enterprise. In this commentary, we describe our difficulties in obtaining research ethics committee (or institutional review board) approval for research into human rights abuses of gay men and lesbians in the South African Defence Force by health professionals during the apartheid era. We use this case study to raise concerns that institutional heterosexism and a reluctance to explore professional abuses of power continue to shape health research in South Africa.

Ethical Issues in Health Research

Since the research-related atrocities of the Nazi regime, there has been increasing awareness of the need to consider ethical issues in research. This has been formalized through the promulgation of government regulations, the development of professional guidelines for conducting research, and the growth of research ethics committees. These committees perform a vital gatekeeper role in assessing the ethics of research proposals and approving only those that meet the standards laid down in the Declaration of Helsinki.[14] Ethics committees also "have a wider responsibility to promote the public interest by helping to ensure that relevant research is done"[15(p1390)]—and, by extension, determining which research does not serve the public interest and therefore should not be done. However, the converse also needs to be considered: to what extent ethics committees may act against the public interest by preventing or retarding research on ideologic grounds.

A literature search of MEDLINE and the International Bibliography of the Social Sciences found surprisingly few articles on the conduct of research ethics committees. A few studies suggested that ethics committees are "wary of [socially sensitive] research and appear to resolve the dilemma posed by [it] by

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Note. The views expressed are the responsibility of the authors.

finding fault more often with [these] protocols."[13(p49)] An experimental study by Ceci and colleagues,[16] in which 157 university institutional review boards reviewed 1 of 9 hypothetical research proposals, found that socially sensitive protocols were twice as likely to be rejected as were similarly designed nonsensitive protocols. Benson[17(p6)] described this study:

> Ethically nonproblematic and nonsensitive proposals nearly always received IRB [institutional review board] approval. However, only 40–50% of ethically nonproblematic, *but socially sensitive*, proposals were likewise approved. . . . IRB disapproval of these proposals were [sic] frequently justified by pointing to alleged methodological deficiencies (for example, inadequate sample size), while nonsensitive proposals rarely received such criticism.

Commenting on this study, Sieber and Stanley[13(p49)] noted that

> the socio-political ideologies of the review committee members appeared to be reflected in the commentary about the rejected protocols. Therefore, although there is nothing that forbids research on sensitive topics, there are powerful forces working against the conduct of such research.

The following case study outlines the responses of a research ethics committee to a potentially sensitive topic: research on lesbian and gay health in the military. By presenting this case study, our intention is not to identify or target a particular institution but rather to illustrate issues that pertain to many research institutions.

The aVersion Research Project

As in military institutions worldwide, many lesbians and gay men have served in the South Africa Defence Force. A submission to the Truth and Reconciliation Commission reported on the use of conversion or reparative therapy by health professionals on several gay conscripts between 1967 and 1978 (*The Health and Human Rights Project: Professional Accountability in South Africa.* Final submission to the Truth and Reconciliation Commission [unpublished report]; Cape Town, South Africa; December 1997). *Conversion therapy* is a term used to describe treatments to convert a person from a homosexual to a heterosexual orientation.[18] No evidence indicates that such therapies can change sexual orientation, and their use is not supported within the field of mental health.[19–21] The Truth and Reconciliation Commission submission noted that "the context was clearly one of being experimented upon, and consent appeared to have been obtained under circumstances of coercion" (*The Health and Human Rights Project: Professional Accountability in South Africa.* Final submission to the Truth and Reconciliation Commission [unpublished report]; Cape Town, South Africa; December 1997:46) (also reference 22). It was believed that the events of this period should be further researched, because they presented an underexamined area of human rights violations and raised important issues of health professional accountability.

A collaborative team, including academic researchers and activists involved with gay and lesbian organizations, developed the aVersion Research Project. The main aims of the research were to explore how health professionals in the South African Defence Force treated homosexual persons and thereby to examine how the military and psychiatry constructed homosexuality as abnormal behavior. The research was to use qualitative methodology. In-depth, semistructured interviews were planned with gay men and lesbians who had received medical treatment in the military, their family and friends, health professionals who may have been involved directly or indirectly, and military personnel. Informed, written consent would be obtained for the interviews, which would be confidential and anonymous.

The initial research protocol was extensively discussed in consultation meetings at several academic institutions, which included input from nongovernmental organizations serving the lesbian and gay community. Thereafter, it was submitted to the research ethics committee of a large medical research institution. Most members of the committee were White male scientists and health professionals appointed by the governing body of the research institution. The committee twice rejected the proposal, raising several different objections in their written responses. The research team was then invited to a meeting of the committee at which problems with the protocol were discussed. Following this meeting, the ethics committee formally approved the study, although with several provisos.

The Research Ethics Committee's Comments

Abuse: A Problematic Concept?

The committee took issue with the use of the word *abuse* in the proposal, suggesting that it was an unsubstantiated assumption and that it implied wrongdoing by health professionals. They questioned whether the conversion treatment given to gay conscripts in the military constituted an "abuse" because (1) "these abuses were a common military phenomenon all over the world at that time" (letter from the chairperson of the ethics committee to the aVersion Research Project, December 15, 1997), and (2) they did not contravene South African law. One member of the committee suggested that to scientifically prove abuse, the evidence would have to be tested in a court of law.

There seemed to be little concern with how the treatments were experienced by those receiving them, which was the main focus of the study. To our knowledge, the committee made no attempt to consult with lesbian and gay organizations that could have represented the viewpoint of that section of society. Indeed, we perceived that the ethics committee was uncomfortable with the subject matter of the research because it involved gay men and lesbians. Given the composition of the committee, it is possible that heterosexist values influenced decision making and led members to see conversion therapy as an acceptable medical treatment because it would address the "problem" of homosexuality.

Our position was that although a particular medical practice may have been professionally or socially sanctioned (although it is debatable whether this was the case in the period covered by our research), this does not preclude it from being considered abusive at the time or subsequently, particularly if treatment was given without consent or under conditions in which informed consent was problematic. Second, we thought that the committee's apologist attitude failed to distinguish between law, which may be country specific and, as in the case of apartheid South Africa, clearly discriminatory, and human rights, which reflect universal moral values. It was disturbing that members of the committee appeared to hold the view that because acts were "legal," they did not contravene the rights of those subjected to them. Unfortunately, this view is held by many South African health and other professionals.[3] In its final approval of the research proposal, the ethics committee made the proviso that words such as *abuse* and *violations* be used more carefully and that *alleged* be added where appropriate (letter from the chairperson of the ethics committee to the aVersion Research Project, March 16, 1998).

Separating Research From Politics

The committee objected to the presentation of the research topic as a human rights issue. They questioned the "political" nature of this sort of research and also challenged whether "a better understanding of society could be gained through a descriptive study" (letter from the chairperson of the ethics committee to the aVersion Research Project, September 4, 1997). Concerns were expressed that the research could be viewed as an investigation into the practices of health professionals in the military "for retribution purposes," linked to investigations initiated by the Truth and Reconciliation Commission. For these reasons, the proposed research was seen as having a "political" rather than a "scientific" purpose and

was therefore deemed partisan and not sufficiently "objective."

This positivist construction of "scientific objectivity" has been extensively critiqued.[3,23] During the apartheid era, the label *political* often was used to undermine and discredit viewpoints that did not support the status quo. Scientific discourse excluded discussion of heterosexism, racism, and other forms of institutionalized discrimination, leaving it decontextualized.[3] The ethics committee appeared to view the apartheid era as "apolitical," yet it constructed research into that past as "political." The committee's comments also could be construed as an attempt to protect fellow health professionals from scrutiny.

Questioning Qualitative Methods

The committee, suggesting that the proposed qualitative sampling methods were likely to bias the research findings, noted that "the sampling causes bias: volunteers will be used, which means they are not looking at the whole picture. In addition subjects will be identified through gay networks/media—which in itself constitutes bias" (letter from the chairperson of the Ethics Committee to the aVersion Research Project, December 15, 1997). The committee suggested that generalizations could not be made from the findings regarding the practices of health professionals in the military and that this perceived limitation, contrary to accepted qualitative methodology, would undermine the validity of the research project.[24]

This case study, and other research, shows that some ethics committees do not always have sufficient expertise to appropriately review the wide range of research methodologies submitted to them.[25] Indeed, the research methodology was the main reason the committee gave for its rejection of the research proposal. However, the committee's responses indicated little understanding of qualitative methodologies. Methodology was being used, both overtly and covertly, as a control device to stop what apparently was seen as undesirable research.

Conclusions

Apartheid provided the ideologic framework for decades of South African health research that allowed racism, sexism, and heterosexism to masquerade as "scientific objectivity."[3,5,6] Despite democratic transition, the enactment of a wide-ranging bill of rights (which includes protection against discrimination on the basis of sexual orientation), and the findings of the Truth and Reconciliation Commission, these hegemonic ideologies have yet to be fundamentally challenged in many institutions in South Africa. The response to our proposal shows how attempts to study abuses of power by these institutions are strongly discouraged.

The findings of the aVersion study confirmed the importance of exploring these hidden histories. In the apartheid era, military policy labeled homosexuality as a "behavioural disorder."[26] Although most lesbians and gay men in the South African military remained "invisible" to the authorities, efforts were made to "combat the phenomenon" of homosexuality by barring homosexual persons from the permanent force and by referring homosexual conscripts to health professionals for medical treatment, sometimes including electric shock conversion therapy.[27] Patients were not given adequate information about the treatments. Consent for treatment was obtained under coercive conditions, sometimes including the threat of internment in a work camp. None of the study respondents reported changes in their sexual orientation as a result of conversion therapy, but most reported long-term negative effects of the treatment, including low self-esteem and depression. We concluded that military health professionals contributed to an environment of institutional heterosexism through their unethical medical practices.[27]

Like health professionals, researchers and research ethics committees do not work within an ideologic vacuum. When heterosexism or homophobia exists, it should be openly discussed rather than hidden behind a facade of debate on scientific validity. If this discussion does not occur, the impression is given that research is being blocked on ideologic rather than ethical grounds. We believe that "ethics that exclude" cannot be in the public interest and in this case represented a form of institutional heterosexism.

Ethics committees can take several steps to redress discrimination. First, the composition of ethics committees should be more representative of society at large and should include both laypersons and representatives of minority groups, such as gay men and lesbians.[28] Second, clear guidelines on the role of ethics committees, particularly for assessing socially sensitive research, must be made available to their members to promote consistency in decision making. Third, ethics committees should receive training on issues of human rights in health. Fourth, the committees should include members with expertise in qualitative methodology, and complex questions about the appropriateness of study designs should be resolved through consultation with experts in the relevant field. Finally, the ethical issues raised by socially sensitive research should be discussed with the research team in an open and constructive manner, with a view to facilitating the research rather than preventing it.

Researchers and research institutions have an important role to play in building a culture of human rights in South Africa and elsewhere. This can be achieved, however, only through inclusion and through ensuring that all research domains, including lesbian and gay health, are supported as valid topics for scientific inquiry. □

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